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Title Page

Long-term Follow-Up after Comprehensive Rehabilitation of persons with epilepsy, with emphasis on participation in Employment or Education

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Abstract

The objective was to describe current situation for patients with epilepsy after rehabilitation with emphasis on employment and education and to investigate if clinical factors at admission were associated with increase in employment or education. All patients that participated in a comprehensive rehabilitation were eligible. Data were collected from medical records at admission to the rehabilitation, at discharge and from a structured telephone interview at follow up 1-17 years after. In total 124 patients participated in the follow-up. Participation in employment or education improved from admission to follow-up in 38 patients. In univariable analysis active epilepsy with tonic-clonic seizures at admission was significantly associated with increased participation in employment or education at follow-up, so was decreased frequency of tonic-clonic seizures from admission to follow-up. The significance of the associations disappeared in adjusted multivariable analysis. Participation in employment or education was improved for many patients at follow up.

Keywords:
Adults
Education
Employment
Epilepsy
International Classification of Functioning
Rehabilitation

1. Introduction

The psychosocial consequences of active epilepsy can be extensive and far reaching [1] Persons with epilepsy have to manage a situation with unpredictable recurrent seizures and in addition often need to live with a stigma and face prejudiced attitudes from their environment. Adding to the burden, comorbidities including depression as well as cognitive deficits and memory dysfunction are common [2-9]. All this can affect self-esteem and self-efficacy, which may contribute to the higher unemployment rate among people with epilepsy [10-11]. To manage these multifaceted problems, some patients with epilepsy may benefit from a comprehensive multi-professional rehabilitation [12-15]. Interventions such as self management groups are quite common, although few have been evaluated systematically [16-18].

In the beginning of the 1990's the Neurological Rehabilitation Clinic at Stora Sköndal, Stockholm, Sweden, developed a rehabilitation program for patients with epilepsy in a day-care setting. The work was inspired by principles of holistic neuropsychological rehabilitation in brain injury, i.e. comprehensive, intensive and structured rehabilitation that integrates cognitive and psychological treatment [19-21] and emphasizing the importance of the whole and the interdependence of the different treatment parts in a therapeutic environment.

The framework of the rehabilitation is based on the WHO's international classification of functioning, disability and health (ICF) that is defined as a process aiming at optimizing the individual's functioning with respect to body functions, activity performance and social participation, also taking into account environmental and personal factors [22-23]The rehabilitation team consists of neurologist, neuropsychologist, physiotherapist, occupational therapist, and social worker. The program targets persons who experience that epilepsy is a hindrance in their activities of daily living and affects negatively their quality of life.

The aim of the present study is to describe in a systematic follow-up the current situation of patients who completed the epilepsy rehabilitation program between 1993 and July 2009, with emphasis on their employment or education (EoE) status. A specific further aim was to identify factors of a favorable development of EoE.

2. Methods

2.1. Patients

Criteria for admission to the rehabilitation program were age from 18-65 years, a diagnosis of epilepsy, perceived difficulties to cope with epilepsy, assumption that the patient was in need of contributions from at least two different professionals in the team. Exclusion criteria for participation were substance abuse, or psychiatric disorder or cognitive decline of such degree that it severely affected the person's ability to participate and communicate in a group setting. All patients having

fulfilled the rehabilitation between 1993 and July 2009 were eligible for the study.

2.2 The rehabilitation program

The rehabilitation is performed individually and/or in groups of 5-6 patients, two to three days/week for eight weeks. The group program consists of psychotherapy, epilepsy education, training in body awareness and relaxation, cognitive counselling/training as well as support in psychosocial issues. The individual rehabilitation can contain all or part of the group program, and in addition often contact with the patient's family and in some cases with employer and workplace. For a more detailed description of the rehabilitation program, see Supplement 1.

2.3 Data collection

2.3.1 Base-line data on admission

Medical records of all patients having fulfilled the epilepsy rehabilitation program at least once during 1993-July 2009 (N=185) were reviewed by one of the authors (EW). Data were collected according to a predesigned protocol, including demographic and clinical data as well as data concerning participation in daily living and society at admission and discharge. Epilepsy data such as etiology, type of seizures and epilepsy were also assessed by a neurologist in the research group (LN).

2.3.2 Follow-up data on current situation

Follow-up data after the rehabilitation was obtained during the period January 2010 – October 2010. All eligible living patients were invited by letter to participate in a structured telephone interview. The interview protocol was similar to the protocol used for the medical record data collection.

2.4. Analyzes and Statistical methods

Participation in EoE was the endpoint of primary interest in the present analysis. To examine changes in participation in EoE we compared the variable "extent of EoE" i.e. no EoE, 25%, 50%, 75% or full time at admission with "extent of EoE" at follow up. The comparison was carried out creating a dichotomous variable with the categories increased or decreased/maintained participation in EoE, respectively. Logistic regression was used to study associations between increased participation in EoE and different clinical characteristics at admission and change of seizure control between admission and follow up. First univariabel (unadjusted) analyses were performed to study associations between EoE and each of clinical factors as age at epilepsy onset, age at admission, duration of epilepsy, neurological comorbidity, and occurrence of tonic-clonic seizures at admission and changes of frequency in tonic-clonic seizures from admission to follow up. Second, adjusted associations were calculated in a multivariable logistic model with all the independent factors.

The associations are presented as odds ratios (OR) with 95% confidence intervals (CI) and *p-value* of <0,05.

McNemar's test was used to test the changes in proportions of patient's participation in EOE, from no participation towards participation, part-or full-time and seizure control, from not seizure free towards seizure free, between admission and follow-up. To test differences between those who participated in the follow-up interview and the drop-outs, i.e. those eligible but that for different reasons did not participate in the telephone interview, we used Independent sample t-test and Fisher's exact test. Other results are presented with numbers and percentages. SPSS 19.0 was used in all descriptions and in the statistical analyzes. Ethical approval was granted by the Ethics Review Board at the Karolinska Institute, Stockholm. Informed consent was obtained from each participant according to the rules of Helsinki declaration.

3. Results

Figure 1 describes the study population and selection process. Out of the 185 patients that had participated in the rehabilitation during the time period, 124 (73.4%) also took part in the follow-up interview and were thus included in our analysis. Most patients had been referred from neurologists, n=104 (84%). Demographic and clinical data at admission for the 61 drop-outs differ in some aspects from the participants. Drop-outs were significantly older (the average age of participants was 36 yrs and of all drop-outs 41 yrs), had lower educational level and had a higher proportion with traumatic brain injury, stroke and brain tumor as etiology of their epilepsy.
The follow-up was conducted 1 to 17 years after admission (median 7yrs, mean 7.3yrs).

3.1. Demographic and epilepsy data at admission and at time for follow-up interview, content of rehabilitation

Demographic and clinical data at admission and at the follow-up interview are shown in **Table 1.** Among the 124 participants 46 were male. Mean age at admission was 36 (range 18-65), male 37 (20-60), female 36 (18-65). The majority had focal epilepsy (91%, n=113). The duration, content and mode (group- or individual treatment) of the rehabilitation are shown in **Table 2**.

3.2 Seizure control

Table 3 presents seizure control at admission and follow-up. About half of the patients (n = 60, 48%) experienced seizures of generalized tonic-clonic type mainly with focal onset the year before admission. Five (4%) had been seizure free at least one year preceding the admission whereas 26 (21%) were seizure free since at least one year immediately before the follow-up. Change in seizure control from admission to follow-up was found in 23 (18.8%) patients, 22 (18.0%) achieved seizure freedom, a significant change in the proportion of seizure free between admission and follow-up ($p < 0.001$). While 16 (13%) deteriorated in seizure control from admission to follow-up, 48(39%) improved **(Table 4).**

3.3Participation in employment or education

Participation in society expressed by ability to work or study was of primary interest in the present study. Thirty-eight patients (33%) had improved in EoE from admission to the follow-up interview. The EoE status at admission and follow-up is presented in **Table 5.** A further 12 patients (10%) had maintained their EoE status. Thirty-two (26%) of the patients participated to some extent in EoE at the time of admission and 56 (45%) at follow- up. A total of 45 patients changed their participation in EoE from admission to follow-up, 35 (30%) patients improved their participation in EoE from no participation in EoE to participate in EoE at some level. There was a significantly higher proportion ($p < 0.001$) involved in EoE, at some level, at follow-up compared with at admission to the rehabilitation

Patients with full-time unemployment, without any income from sickness insurance, were 9 (7%) at admission. At follow-up 7 (6%) patients were full-time unemployed and 9 (7%) patients part-time unemployed. Among those that were not active in EoE, the majority considered epilepsy to contribute to the work-barriers.

No patient with primary school as their highest education level at follow up had improved in EoE status. 31 patients (25%) went through some kind of educational programme during the follow up period, of which 45 % also improved in EoE.

3.4. Associations between clinical factors at admission and changes in EoE from admission to follow up

For the majority of patients the participation in EoE was unchanged from admission to follow-up, n = 62 (53%). A decreased participation was seen in 16 (14%) persons, whereas thirty-eight (33%) persons showed an increased participation in EoE.

The association between different clinical characteristics and an increase in EoE participation is summarized in **Table 6**. Patients that retired between admission and follow-up (n=8) were excluded from this analysis. No association between gender or time from admission to follow-up interview and improved EoE was found (not shown in table). Unadjusted logistic regression models revealed that having tonic-clonic seizures during the year prior to admission was associated with increased participation in EoE, as was improvement in tonic clonic seizure frequency from admission to follow up. However, when adjustment was made for all factors these associations were no longer statistically significant.

4. Discussion

In this follow-up study of 124 patients that had completed an epilepsy rehabilitation program, thirty-eight patients (33%) showed improved participation in society expressed as EoE status from admission to follow-up on average 7.3 years after the rehabilitation. In our unadjusted analysis, active epilepsy expressed as occurrence of tonic-clonic seizures during the year preceding admission, and improvement in

control of tonic-clonic seizures from admission to follow-up were associated with increased EoE participation. There was no significant association between age at admission, age at epilepsy onset, epilepsy duration at admission, gender, time between admission to follow-up or neurological co-morbidity and improvement in EoE. Additionally, when adjustments were made simultaneously for all these factors, the association between tonic-clonic seizures and improved EoE, OR (95% CI) 1.7 (0.5-5.8) and reduced frequency of tonic-clonic seizures and improved EoE, OR 2.6 (0.8-8.8) was no longer significant. Hence, we were unable to identify clinical factors that would predict improved EoE participation at follow-up after rehabilitation.

This is a descriptive study and not a randomized controlled trial and we can thus not with any certainty ascribe changes in the patients' status to the rehabilitation program as such. Although the data were collected systematically, the lag time from rehabilitation to follow-up assessment ranges from 1-17 years adding to the interpretation difficulties. The association between occurrence of tonic-clonic seizures at admission and improved EoE status at follow-up could, however, be interpreted as an indication that our rehabilitation might be particularly effective in patients with more active epilepsy. On the other hand, improved control of tonic-clonic seizures from admission to follow up was more strongly associated with improved EoE, and there is a likely interaction between these two variables. Obviously, only those patients that had poorly controlled tonic-clonic seizures at admission could improve in this regard during follow-up. Better seizure control might thus be the important factor for improved EoE participation, and changes in seizure control could be due to factors unrelated to the rehabilitation program such as subsequent modifications of medication or other therapeutic interventions. Although optimization of the medical treatment is not normally included in the rehabilitation program, it is possible that the patients' improved knowledge about their epilepsy and the basic principles of treatment can enhance compliance with the treatment and also facilitate the communication between the patient and the prescribing physician.

The strengths of our study are the size of the study population, the fact that we have obtained data of each patient who underwent the program since its start in 1993, and that a large proportion of eligible patients participated in the follow up interview. This is the only epilepsy specific rehabilitation program in the greater Stockholm region. Hence our data likely reflect the situation for patients from the region that have been subject to a structured rehabilitation. It is nevertheless difficult to generalize from our observations to what the effects might have been in patients that have not been referred to Stora Sköndal because of the unknown selection process for referring patients to the rehabilitation. Only a few of our patients were self referrals, whereas the large majority was referred by neurologists having identified a need for multi-professional epilepsy focused rehabilitation for the patient. Hence the patient population is highly selected.

As an objective and quantifiable endpoint, EoE status was chosen as the endpoint of this study although this in fact is not the primary goal of the rehabilitation program, which does not include a formal vocational rehabilitation. However, assessment of neuropsychological functions, activity

analyses and discussions of future job plans, also together with the workplace, school, social insurance and employment services, are often included, as is referral to vocational rehabilitation or employment services at discharge when required, see supplement. Outcomes of vocational rehabilitation services for people with epilepsy in Missouri US were analyzed by Mount et al (2005). Among demographic factors, cost of and type of vocational rehabilitation interventions (epilepsy data were not available) the only variables associated with successful vocational outcome were training and job services such as on-the-job support. Studies of vocational rehabilitation and employment status are however difficult to compare, since conditions vary significantly in different countries and in different time periods also depending on political changes in society, not only for people with epilepsy [24].

The present study is the first analysis of admission status and follow-up data on all patients participating in the comprehensive holistic epilepsy rehabilitation program of Stora Sköndal. Although the situation was improved for many patients at follow-up, it is not possible to strictly determine the contribution of the rehabilitation to this change. This would require a prospective randomized study. The present analysis forms the basis for the design of such a planned prospective study in which referred patients could be randomized to immediate or deferred participation in the rehabilitation program.

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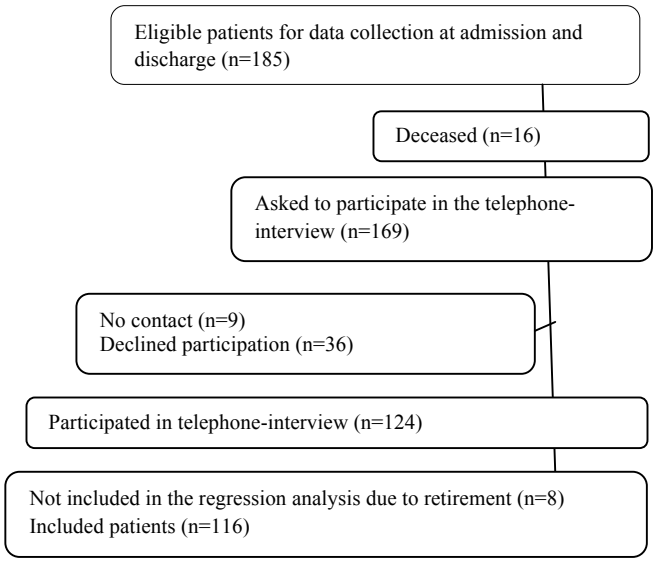

Fig. 1. Flow chart for the selection process

Table 1

Demographic and clinical characteristics of the patients. (n=124)

	Admission	Follow-Up
	n(%) or mean(SD)(Range)	n(%) or mean(SD)(Range)
Gender, tot n(% Female)	124(61.3%)	
Age at onset	21(14)(0-64)	
Infant/child <1-12	30 (24%)	
Adolescent 13-17	36 (29%)	
Adult >18	58 (47%)	
Comorbidities		
Neurological, with or without other comorbidity [a]	43 (35%)	
Mental disorder, with or without other comorbidity [b]	23 (19%)	
Other somatic co-morbidity	10 (8%)	
No co-morbidity	48 (39%)	
Aetiology		
Pre/Perinatal abnormality	15 (12%)	
Trauma CNS [c]	5 (4%)	
Status post Stroke	7 (6%)	
Neoplasm CNS [c]	10 (8%)	
Infection CNS [c]	11 (9%)	
Others: MS [d] , SLE [e], AVM [f]	4 (3%)	
Mesial temporal sclerosis	3 (2%)	
Idiopathic	9 (7%)	
Unknown	60 (48%)	
Type of epilepsy		
Generalized idiopathic	9 (7%)	
Localized symptomatic	55 (44%)	
Localized cryptogenic	58 (47%)	
Unknown	2 (2%)	
Duration of epilepsy (yr)	15(12)(0-48)	23(14)(3-63)
Time from admission to time for interview (yr)		7.3(4.6)(1-17)
Age	36(11)(18-65)	44(12)(24-75)
Antiepileptic drug (AED)		
Monotherapy	35 (28%)	31 (25%)
Polytherapy	84 (68%)	86 (69%)
No AED	5 (4%)	7 (6%)
Epilepsy Surgery		
Yes	13 (10%)	17 (14%)
Living condition		
Single	29 (23%)	45 (36%)
Own family	76 (61%)	71 (57%)
Parents	19 (15%)	8 (6%)
Education level		
Compulsory primary school	20 (16%)	18 (15%)
Upper secondary school	78 (63%)	74 (60%)
Higher education e.g. University	26 (21%)	32 (26%)

[a] Including mental disorders. [b] Not including neurological co-morbidities. [c] Central Nervous System.
[d] Multiple Sclerosis [e] Systemic Lupus Erythematosus. [f] Arteriovenous Malformation.

Table 2

Time periods and rehabilitation design

	Male n=48(39%)	Female n=76(61%)	Total
	n(%)or mean(median)SD(range)	n(%)or mean(median)SD(range)	n(%)or mean(median)SD(range)
Years from admission to follow-up	7.9 (7)5(1-17)	6.9 (6)4(1-17)	7.3 (7)5(1-17)
Years from discharge to follow-up	7.4 (7)5(1-17)	6.5 (6)4(1-17)	6.9 (6)5(1-17)
Weeks from admission to discharge	26.5 (18)23(6-117)	26.4 (21)20(5-122)	26.5 (20)21(5-122)
Number of rehab days	32.6 (26)22(8-88)	32.6 (26)21(6-122)	32.6 (26)21(6-122)
Rehab design			
Individual rehab	13 (10%)	11 (9%)	24 (19%)
Group rehab	14 (11%)	25 (20%)	39 (31%)
Individual and group rehab	21 (17%)	40 (32%)	61 (49%)

Table 3

Seizure frequency 12 months prior admission and follow-up (n=124)

	Admission n(%)	Follow-up means(SD)(range)
Tonic-Clonic seizures		
0-2 Seizures	82 (66%)	92 (74%)
3-52 Seizures	37 (30%)	22 (18%)
>52 Seizures	0 (0%)	10 (8%)
Not seizure free, frequency unknown	5 (4%)	0 (0%)
Data missing	0 (0%)	0 (0%)
Other seizures		
0-2 Seizures	15 (12%)	41 (33%)
3-52 Seizures	50 (40%)	45 (36%)
>52 Seizures	41 (33%)	30 (24%)
Not seizure free, frequency unknown	18 (15%)	6 (5%)
Data missing	0 (0%)	2 (2%)
Total seizure frequency		
0-2 Seizures	9 (7%)	29 (23%)
3-52 Seizures	53 (43%)	45 (36%)
>52 Seizures	46 (37%)	38 (31%)
Not seizure free, frequency unknown	16 (13%)	10 (8%)
Data missing	0 (0%)	2 (2%)
Occurrence of seizure		
Seizure free	5 (4%)	26 (21%)
Not seizure free	119 (96%)	96 (77%)
Data missing	0 (0%)	2 (2%)
Seizure freedom (yr)		7.6(8)(1-30)

Table 4

Changes in seizure frequencies from admission to follow-up (n=124)

		n(%)
TC seizures	Increased	26 (21%)
	Decreased	38 (31%)
	No change	57 (46%)
	Missing data	3 (2%)
Other seizures	Increased	17 (14%)
	Decreased	55 (44%)
	No change	34 (27%)
	Missing data	18 (15%)
Total seizure frequency	Increased	16 (13%)
	Decreased	48 (39%)
	No change	41 (33%)
	Missing data	19 (15%)

Table 5

Participation in Employment or Education (EoE) (n=124)

	Admission		Follow-up	
	n	(%)	n	(%)
Employment or education status				
Full time EoE	20	(16%)	29	(23%)
Part time EoE	12	(10%)	27	(22%)
Not active in EoE				
Full-time sickness absence[a]	82	(66%)	50	(40%)
Part-time sickness absence[a]	12	(10%)	25	(20%)
Full-time unemployment	9	(7%)	6	(5%)
Part-time unemployment	0	(0%)	10	(8%)
Retired	1	(1%)	8	(6%)
Cause of work barriers				
Epilepsy, with or without other causes	76	(62%)	71	(59%)
Other causes	16	(13%)	12	(10%)

[a]Include Sick leave, Sickness compensation and Disability pension.

Table 6
Association between clinical factors and increased participation in EoE (n=116 [a])

Variables and categories	Female n(%)	Total n [b]	Active in EoE at admission n	Increased	Unadjusted		Adjusted [c]	
					OR (95% CI)	*P* value	OR (95% CI)	*P* value
Age at admission								
Age 18-34	37(63%)	59	14	37%	1.5(0.7-3.3)	0.29	1.0(0.4-2.7)	0.93
Age >=35	39(60%)	57	18	28%	reference		reference	
Age at onset								
Age <=17	44(67%)	63	16	40%	2.0(0.9-4.5)	0.09	1.7(0.5-6.1)	0.40
Age >=18	32(55%)	53	16	25%	reference		reference	
Duration at admission								
>=11 years		63	18	37%	1.6(0.6-4.0)	0.32	1.2(0.4-3.7)	0.76
0-2 years		19	3	32%	1.3(0.4-4.4)	0.69	1.8(0.4-7.7)	0.41
3-10 years		34	11	26%	reference		reference	
Comorbidity								
Neurological disease/injury		39	9	28%	reference		reference	
No neurological disease/injury		77	23	35%	1.4(0.6-3.2)	0.46	1.4(0.5-3.4)	0.52
Occurrence of T-C seizures, last 12 months								
Seizure free		60	22	20%	reference		reference	
Not seizure free		56	10	46%	3.5(1.5-7.9)	0.003	1.7(0.5-5.8)	0.39
Changes of frequency in T-C seizures								
Increased/No change		78	25	23%	reference		reference	
Decreased		35	7	54%	4.0(1.7-9.2)	0.001	2.6(0.8-8.8)	0.13

[a] 8 patients not included due to retirement pension. [b] Total number in unadjusted model

[c] Adjusted for all six variables presented, n=113